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Genetic privacy and non-discrimination

Report of the Secretary-General

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Note verbale

[Original: Spanish]

The Permanent Mission of Cuba to the United Nations presents its compliments to the Secretariat of the United Nations and has the honour to refer to note OESC/O6/148 requesting the opinions of Member States on resolution 2004/9 of the Economic and Social Council, entitled "Genetic privacy and non-discrimination".

Cuba attaches great importance to the efforts being made within the framework of the United Nations system to promote an ethic of life sciences, and, in particular, to ensure the effective implementation of the right of all individuals and peoples to benefit without any discrimination from advances in science and technology and their applications, with guarantees of protection and due privacy, by virtue of the relevant international instruments, including the above-mentioned resolution of the Economic and Social Council.

Cuba, which has been subject to a stringent economic, trade and financial embargo imposed by the United States, has a long and proud history of promoting and protecting genetic privacy and non-discrimination, consistent with its commitment to the promotion and protection of all human rights for all. Evidence of this has been the series of measures it has adopted to preserve the genetic privacy of its citizens and to ensure non-discrimination against them, as follows:

1. The Cuban National Genetic Network, comprising 184 medical genetic centres throughout the country, is regulated by a set of ethical norms governing the use of the genetic information of Cuban citizens who benefit from public assistance or participate in genetic research. These norms apply also to access to samples of such materials stored in banks for purposes of study.

2. An equally rigorous system exists for establishing the technical requirements and bioethical principles for the handling of biological samples and genetic data banks.

3. A national referral centre for the Cuban programme for the diagnosis, treatment and prevention of genetic diseases, the National Centre for Medical Genetics, directs the methodological aspects of the work of the National Network.

4. A Committee on Research Ethics operates within the National Centre to ensure protection of the rights, safety and well-being of individuals, ecosystems and social groups that are subjects of scientific research and to monitor the scientific validity of and ethical and social justification for scientific and technical projects undertaken in the country by the network of medical genetic centres.

5. On the recommendation of the above-mentioned Committee on Research Ethics and in conformity with the provisions of the Universal Declaration on the Human Genome and Human Rights, a series of ethical norms were adopted for the use of the genetic information of Cuban citizens participating in research or whose screening for public assistance yields data about the individuals and/or their family members.

6. These norms regulate the purposes for which genetic data may be collected, the consent to do so, the resulting genetic evaluation, access to information, confidentiality and privacy, as well as the use, destruction and cross-referencing of data.

7. Also subject to regulation is the conduct of predictive testing in the country's medical genetic services, which is aimed at standardizing the operations of the various services and ensuring compliance with the universally accepted ethical norms in this field.

8. Thus, to cite but one example, a series of laws, regulations and other measures have been enacted in Cuba to ensure that persons affected by HIV are not subject to any discrimination and are able to enjoy the same rights as any other citizen, in other words, to receive free medical care (including antiretroviral treatment), free education, social security, jobs and participation in all activities that their physical and intellectual situation allow.

9. It must be added that what we refer to as bioethics committees have been established in Cuban scientific and health institutions. The personnel working in these institutions are subject to a strict code of ethics which they swear to uphold before embarking on their professional activities. The ethical values of Cuban scientific and health personnel not only include those aspects that are recognized in the relevant resolutions of the General Assembly of the United Nations, the Commission on Human Rights, the World Health Organization and the United Nations Educational, Scientific and Cultural Organization, but which are based on the conviction defended by the Cuban national hero, José Martí, namely, "*Patria es humanidad*" (the homeland is the human race). Internationalist solidarity has inspired the work of thousands of Cuban teachers, doctors and paramedical personnel, who have provided their expert services in numerous countries of Africa, Asia and Latin America.

Cuba takes this opportunity to share its concern at the misuse of technical and scientific advances. In the current conditions of injustice in today's international economic and political order, science can and indeed has become a factor that exacerbates inequalities and a dangerous factor for the spread of terror based on superiority and military threat, imperialist aggressions and other manifestations of international terrorism. Cuba will promote and support wherever possible international efforts to promote cooperation and the peaceful use of science.

The Permanent Mission of Cuba to the United Nations takes this opportunity to convey to the Secretariat of the United Nations the renewed assurances of its highest consideration.